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The 'ME Bandwagon' and other labels:

Constructing the genuine case in talk about a controversial illness.

Abstract

This paper examines the discourse of morality surrounding 'ME' as a contested illness, looking at how GPs and ME group members differentiate between the category of 'genuine ME sufferer' and the 'bandwagon'. 'Jumping on the bandwagon' is a metaphor commonly used to describe the activity of 'following the crowd' in order to gain an advantage. This discursive analysis shows how 'bandwagon' categories are constructed in contrast to the category of genuine sufferer. People who jump on the bandwagon are accused of matching their symptoms to media stereotypes, adopting trendy illnesses ('fads',) or using 'tickets' to avoid facing up to psychological illnesses. Both GPs and ME group members construct a differential moral ordering of physical and psychological illness categories, where the latter assumes a lesser status. The paper concludes that against a background of medical uncertainty and controversy, the 'bandwagon' and other derogatory labels function as contrast categories that work to establish the existence of 'ME' as a genuine illness.

Key words: Discursive psychology; ME/CFS; physical/psychological; contested illness; 'bandwagon'.

ME (myalgic encephalomyelitis) has been associated with medical uncertainty and scientific debate since before the 1950s (See reports of the Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996; and Westcare, 1994). Although ME research has aimed to identify the incidence, nature and causes of the illness, it has often raised more questions than answers regarding the status and existence of the illness as physical or psychological. The process of medical scientific research, and the resulting claims and counter-claims surrounding that process, have given rise to a range of diagnostic labels and opinions about the nature of a disease, illness (or category of illnesses) commonly referred to as ME or CFS (chronic fatigue syndrome)[1]. Sharpe (2005: 270) points out that CFS as a diagnosis is quite 'literally the construction of committees'. The 'ME/CFS debate' and other controversial medical conditions such as Repetitive Strain Injury (Arksey, 1998; Horton-Salway, 1998) raise similar ontological questions: Is there really any solid evidence for the existence of a separate disease entity and if so what label should be used? This paper does not attempt to answer such questions, but will examine some of the discursive strategies used to construct ME as a distinct entity and to distinguish the 'genuine' case in opposition to 'bandwagon' categories.

The origin of the 'ME debate' depends on whether the writer defines the object of study as a new disease entity (The Lancet, 1956: 790) or whether it is categorised as an older and more established psychiatric condition that has existed under a different label, 'old wine in new bottles' (Wessely, 1990) [2]. The former account takes a realist view of a disease as a pre-existent entity waiting to be discovered, whereas the latter account treats constructions of disease as culturally relative. In this case, the 'old wine' is arguably a psychological state.

It is against this background of controversy about the nature and existence of an illness, that discourse studies on CFS and ME have analysed settings such as clinics (Banks and Prior, 2001), 'patient schools' (Bülow, 2004) research interviews and self-help groups (Horton-Salway, 1998; 2002; 2004; Tucker, 2004). The Banks and Prior study (2001: 12) describes how the attributions of patients and their doctors are played out in the clinic as 'a contest between the doctor and the patient to define the true nature of the patients' illness'. Similarly Horton-Salway describes how psychosocial identities are produced in tandem with attributions of physical or psychological illness and the deployment of different diagnostic labels. In the context of interviews, negative psycho-social identities are constructed by GPs who wish to justify a diagnosis of psychosomatic illness, malingering or 'all in the mind'. Positive psychosocial identities are attributed to people who are seen to suffer from a 'genuine' physical illness. Tucker's study shows that sufferers position themselves as having a legitimate physical illness so as to *avoid* the stigma of psychological disorder.

'Troubled' Identities

A contested category such as 'ME' is inevitably associated with 'troubled identities' that have to be worked for and negotiated (Gubrium & Holstein, 2001). One way that such identities are constructed and solidified is through 'formula stories' that are built from shared experience in support groups (Loseke, 2001: 109). In that context, it is common for individual stories to be counted either as prototypical examples of a collective experience or as marginal cases (c.f. Maines, 1991). In patient schools, the differences between diagnostic categories tend to be minimised for the purposes of

establishing a collective narrative of shared experience in order to support members (Bülow, 2004). Support groups are thus engaged in the '*collaborative production of identities'* where individual stories are 'not allowed to veer much from institutionally preferred themes, plots and characters' (Loseke, 2001: 121). Such studies typically describe how the existence of the authentic case is built through the members' rehearsal of narratives that construct shared experience.

In other contexts, it is the differences between 'person categories' that are more likely to be emphasised. Studies of workplace practices have shown how 'typifications' are commonly used by professionals to differentiate client groups (Schutz, 1971). Examples include Hargreaves (1977) on 'types of pupils'; Murcott (1981) on 'good and bad patients'; and Stimson (1976) on 'trouble and types of patient'. Harvey Sacks (1979; 1992) demonstrated that such 'person categories' are routinely employed in the business of such interactions. The allocation of individuals to different 'person categories' (such as good/bad patients), or minimising difference in constructions of shared experience and attributes in common (such as support group members) are clearly a situated discursive accomplishment.

The study of 'categories in use' (Edwards, 1991; Jayussi, 1984; Sacks, 1972; 1992) examines the situated-ness of category construction. It involves analysing the ordinary methods that people use to construct social categories and define the boundaries of group membership (Antaki & Widdicombe; 1998; Hester & Eglin, 1997; Potter, 1996; White, 2002). In one such example, a study of youth sub-cultures, Widdicombe & Wooffitt (1995) demonstrated how categorising oneself as a genuine 'Punk' or 'Goth'

was established, through a display of resistance to popular stereotypes, in contrast to those who 'latched on' or superficially conformed to peer influence.

This paper analyses the discourse of GPs and ME support group members to investigate the following areas of interest: How are ME/CFS (and other labels) constructed as illness categories? How do GPs and ME support group members construct the 'genuine' case? What are the implications of their constructions?

Methodology

The methodology used in the following analysis is qualitative. The data was collected by two methods, semi-structured interviews (initially with ten GPs and ten ME group members) and also using 'naturally occurring' talk from an ME support group. The informal nature of the interviews allowed the GPs and the group members to talk about the topic of ME/CFS and also more specifically, about their own experiences as GPs or sufferers. The same kinds of questions and topics were raised in all of the interviews: The GPs were asked to talk about their experience of ME/CFS and to describe some cases from their own medical practice. ME/CFS sufferers were asked to tell the story of the illness and how it started. All interviews took a more or less unstructured form and there were lengthy stretches of narrative in which the interviewer says nothing. Where a data extract does not follow on directly from an interviewer question, I have indicated how that extract relates to a question or topic that the interviewer introduced at an earlier point. The support group data was taken from a more 'naturalistic' setting, being drawn from a monthly meeting where a guest speaker was invited to talk to the group about 'A Clinical Psychologist's view of ME/CFS'. This talk and the discussion that followed were recorded by the group members for their library of resources for use by housebound members. This was a

matter of routine for all present, who granted me permission to duplicate the recording for research purposes. The data can therefore be counted as 'naturalistic' in the sense that both the discussion and recording are what happened naturally at the meeting and were not set up for research purposes (Potter, 2002).

Data from these two settings is analysed to show how 'The ME bandwagon' is a relevant category for GPs (who act as 'gatekeepers' for diagnosis) and for the members of the ME group (who seek a legitimate medical label for their illnesses). Whilst previous research on ME/CFS has focused on analysing narratives of illness experience (Tucker, 2004) or the cultural context of illness narratives (Ware, 1992) or the way that CFS sufferers construct illness attributions (Abbey, 1993) none of these studies have used discursive psychology to analyse the accounts of ME/CFS sufferers alongside GPs accounts of their patients. The reason for including these two different participant groups is that both the GPs and ME/CFS sufferers do similar work to 'police the boundaries' of the legitimate illness category and define who is entitled to membership. The analysis therefore identifies those data extracts where the common thread is the construction of genuine cases in contrast to non-genuine cases.

The method used for analysis of the data is discursive psychology (DP) (Edwards & Potter, 1992; Edwards, 1998; Potter, 2003; Potter & Edwards, 2001) and the data has been transcribed according to Jefferson conventions, suitable to this kind of analysis (Appendix). Social categorisation and social identity have traditionally been theorised in social psychology as a cognitive-perceptual phenomenon that can be investigated using experimental methodology (Tajfel, 1981; 1982; Turner, 1987). Likewise, medical reasoning is more often regarded as a cognitive process of categorisation.

Since Sacks's (1979; 1992) pioneering work on the discursive study of categories in use, writers such as Edwards (1991; 1998); Hester and Eglin (1997); and Jayussi (1984) have studied how categories are used in everyday talk to construct the moral order. This includes 'defining and policing group membership' (Edwards, 1998: 16).

Following a discursive psychology rationale, data transcripts were studied repeatedly to gain a thorough familiarity with the kinds of categories that are constructed (illness labels, person-categories) and what kinds of actions are performed through the use of such categories in the talk. Apart from looking at the constitutive nature of what is said, it is also the rhetorical function of participants' discourse that is of interest. How are contrastive categories of illness labels and person categories used to construct different explanations about the nature of ME/CFS? How are categories constructed and linked together in accounts that establish a moral ordering of illness?

Analysis

The terms 'ME' and 'ME sufferer' are not neutral ones since this is a contested illness and a controversial diagnostic label (Horton-Salway, 1998). The term ME is often used interchangeably (or in recent official documents) merged together with CFS (Sharpe, 2002). As the analysis in this paper shows (and others have observed) the term 'ME' is preferred by people who define the illness as physical disease and differentiate it from other forms of chronic fatigue conditions. Medical practitioners do not always agree the use of the label 'ME' and all that it implies (Huibers & Wessely, 2006) and the different explanations entailed in the use of labels is an important aspect of what participants talk about in the data extracts, below. My analysis does not set out to privilege one label (or one explanation of the illness) as being more accurate than another. Rather, the aim is to examine the discourse to

identify what is being constructed, how it is being constructed and what actions are performed when speakers use these constructions.

Three features of discourse are examined in this analysis: the constructed and relational nature of the illness categories; the construction of 'insider-outsider' categories and the moral organisation of those categories. The analysis is organised in three sections.

1. The co-construction of a contested illness category.
2. How GPs use psychological categories in accounts of false claims.
3. How ME group members establishing the 'genuine case' in contrast to the 'bandwagon'.

1. The co-construction of a contested illness category

In this section of analysis, two different health professionals negotiate and establish their grounds for talking about ME. A GP talks in an interview (Extract 1) and a Clinical Psychologist talks in a support group meeting (Extract 2). The analysis examines these accounts to see how they define the meaning of ME in relation to other diagnostic labels.

Extract 1: (Interview with GP)

1.	**I**	When did you first become aware of-of the illness known as ME?
2.		(3)
3.	**Dr S**	In the <u>form</u> of ME? (.) or-in-what we used to know it as?
4.	**I**	(what was that?)
5.	**Dr S**	In that (.) post-viral fatigue-fatigue syndrome (.) I suppose I'd been

6. diagnosing in general practice fifteen years ago (.) still not quite sure

7. (.) what ME is as a diagnostic (.) category

Extract 2: (Support group discussion: FM= speaker; CR= goup member)

1. FM Chronic Fatigue is an umbrella term (.) and within that there are lots

2. of types of Chronic Fatigue Syndrome (.) and ME is one particular

3. sub-type (.) of Chronic Fatigue Syndrome (.) so I don't know (.) I was

4. going to talk about Chronic Fatigue Syndrome (.) so I don't know if

5. you see that as (.) I mean do you see that as the same thing or do you

6. see that as-as-as (.) er different (.) is there a difference between

7. Chronic Fatigue and ME?

8. CR I was told by the physician at the hospital (.) that Chronic fatigue

9. Syndrome (.) or Post-Viral (.) was what a lot of people got after

10. suffering from a very bad vi:rus (.) and this would probably last for

11. about eighteen months (.) two years (.) and then if that person didn't

12. recover (.) er and continued with the symptoms or got worse (.)

13. er (.) then they then say you've got ME (.) er but initially it would be

14. diagnosed as CFS or post-viral syndrome

The first two extracts show how the participants use labels to construct different illness categories, to contest them, to construct boundaries around them and talk about their meanings in relation to each other.

In interviews, as with other forms of interaction, participants work to establish their own grounds for answering questions and negotiating the meanings of terms. The controversial status of 'ME' is established in the first extract, where the interviewer nominates the topic (the GP's experience of ME patients). The term 'ME' is marked as a problem by both the interviewer's question and the GPs' response. The format of the interviewer's question ('the illness known as ME') sets up an ambiguity (line 1) which is continued in the insertion sequence that follows (lines 1-4) where a long pause and a 'question-seeking-clarification/confirmation' indicate that there is some interactional 'trouble' in this sequence of talk (Schegloff, 1972; Widdicombe & Wooffitt, 1995: 96). The GP re-specifies the topic (line 3) and then suggests an alternative label, post viral fatigue syndrome (lines 5-6) which is qualified as a more familiar category than ME. In doing this the GP constructs for himself a firmer knowledge base for participating in the interview (lines 5-6: 'been diagnosing in general practice fifteen years ago'). Not only does this *contest* the interview topic, but it also constructs 'ME' as an entity that has been around for a long time under a different label. Woolgar and Pawluch (1985) identified this kind of discursive strategy as ontological gerrymandering, a kind of 'selective relativism'. One aspect of reality is treated as constant (the illness as an entity) whilst another aspect of reality is treated as constructed (the label and its meaning). Pollner (1987) later described this strategy as the form of mundane reasoning that is used to resolve 'reality disjunctures' in cases where disagreements threaten the existence of an ultimate truth lying beyond people's versions. Whilst Pollner's analysis refers to forms of reasoning used in the courtroom, here it is used by the GP, in the context of talking about a disputed medical category. Where controversy threatens to undermine the foundation of medical knowledge,

'selective-relativism' functions here to establish a stronger evidence base and provides a firmer basis on which to speak with authority in the interview.

The support group talk in Extract 2 shows how members of an ME support group and their visiting speaker (a Psychologist) struggle to establish some common ground whilst establishing and maintaining their differences about the categories ME and CFS. Like the GP in the interview (Extract 1), the Psychologist (FM in Extract 2) is careful to mark out his own grounds for participating in the discussion, starting with his definition of ME as a 'sub-type' of Chronic Fatigue Syndrome. The Psychologist is an invited speaker to the support group and, as a Psychologist, he has a clear 'stake' in persuading the members to accept his preferred explanation for their illnesses, his use of the label CFS and the advice he has on offer. On the other hand, the support group members have adopted the label ME and its association with physical illness. This much is clear from their naming of the support group (an 'ME group') and their invitation to the Psychologist to speak about his view of 'ME'. Against this background, the Psychologist's use of the term CFS (in Extract 2) marks chronic fatigue as the *defining* characteristic of a common condition. Its equivalence with ME as a fatigue condition is a construction that is clearly contested by group member (CR) who categorises CFS and ME so that they blur into one another as a developing and worsening illness trajectory from 'very bad virus' to 'CFS or post-viral' to 'ME'. Instead of being constructed as 'nested' categories implying equivalent fatigue conditions, CFS is here being differentiated from a more serious post-viral illness that leads to ME. By establishing a *chronological* ordering of category membership, CR distinguishes ME as a potentially serious and long lasting condition that follows a

viral disease. This account of ME emphasises the physical nature of the illness in contrast to some non-specific fatigue condition implied by the term CFS.

2. GPs' 'psychologised' accounts of false claims

Motives, 'fads' and 'tickets'.

The health professionals in Extracts 1 and 2 have constructed ME as a problematic category and suggested alternative labels as more appropriate. In the following extracts, the GPs go further and query the motives of people who use the label, ME, or seek this diagnosis (Extracts 3-5). In doing so the GPs suggest that their patients; illnesses have a psychological cause.

Extract 3: (Interview with GP)

At one point in the interview, Dr B talked about the way some patients bring him articles on ME from magazines and from national support groups. This led to the following interviewer question on self-diagnosis:

1. **I** Right, so do you get a lot of people self-diagnosing?

2. **Dr.B** Ye::s (.) yes (.) you see I think the thing is heh I mean obviously when

3. we don't fe:el well and we try to make sense of it (.) and we want a

4. name for it (.) u::m (.) because if you've got a name for it (.) it makes

5. us feel safer (.) that we're not at the whims of some random (.)

6. whatever (.) or we're going mad or (.) so I think we desperately want a

7. name (.) and if it is a name whereby somebody else is going to have to

8. get us better (.) as opposed to sort of saying (.) "yeah I'm running my

9. lifestyle (.) or I'm running my marriage or (.) my job (.) in a way that

10. wearing me out and exhausting me" (.) then the onus is then on me to

11. fix it (.) and it's far easier if somebody else can fix it for me (.) y'know

12. so I think a lot of people want the diagnosis of ME because they then

13. think that that's going to (.) either make it easier or somebody else will

14. be able to cure it (.) u::m

In Extract 3, Dr B represents some of his patients (who are marked by the interviewer's question as 'self-diagnosing') as motivated to seek a medical label for everyday social, lifestyle and relationship problems. Using generalised categories such as 'people' and inclusive phrases like 'we don't feel well', 'we're going mad' and by referring to 'my lifestyle' 'my marriage' 'my job', Dr B constructs an account of patients who seek a diagnosis of ME. Although he aligns himself with this patient group using terms like 'my lifestyle' 'my marriage' 'my job', he identifies a certain group of patients who suffer ordinary distress that is related to their everyday lives and are highly dependent on doctors. He suggests (lines 4-8) that their adoption of a label puts the onus onto the GP and is used by such patients to avoid personal responsibility for sorting out their lives. The GP in the next extract also refers to patients' avoidance strategies.

Extract 4: (Interview with GP)

Prior to this extract, Dr M has identified 'lethargy' as a symptom of ME. The interviewer picks up this thread in the next question.

1. I Is lethargy the [main presenting symptom?

2. Dr M [yeah

3. **(**2.0)

4. Dr M **‘**C<u>an’t</u> do this’ and ‘<u>can’t</u> do that’

5. **(**3.0)

6. but that (.) that powerful feeling can also be a sign of depression

7. I Following an event? Or a set of circumstances?

8. (4.0)

9. Dr M I don’t know all the cases in a detailed way to say ‘yeah or nay’

10. (4.0)

11. Dr M I mean I think (.) most doctors will say that er (.) the worry with this

12. sort of type of label is that it’s a handy ticket (.) people who’ve got

13. (1.9)

14. Dr M problems and want to label them as opposed to (.) going for the

15. problem

The lengthy pauses in extract 4 suggest that this is a section of ‘troubled talk’. The pauses at lines 3,5, 8, 10 ad 13 show that this GP (like one in extract 1) orients to the topic of ME, particularly his suggestion that patients are suffering from psychological problems, as a potential source of trouble in the interview itself. He describes ME as a ‘type of label’ that is ‘a handy ticket’ (line 12). Lines 14-15 construct patients as seeking a ‘ticket’ to avoid an underlying ‘problem’ which is spelled out (at line 6) as ‘depression’. The term ‘ticket’ used in this context is an interesting one that brings with it a whole range of implications. A ticket is normally used to gain access to a resource, which, in this case is legitimate access to the sick role and a physical illness label. Patients who seek such a label are described as avoiding their real psychological

problems (depression), they ‘want to label them’ (line 14) and the ‘facts’ of psychological illness are treated as an underlying truth which the label (‘ME’) is used to cover over. In both extracts 3 and 4, psychological illness is clearly constructed as the to-be-avoided category that is contrasted with ME-as-a-physical-illness for which patients need take no responsibility. The to-be-avoided category is ostensibly a description of what *patients* believe about illness categories, and the GP is not saying that *he* sees psychological illness in this way: On the contrary, if only they would ‘go for the problem’ (lines 13-14) then the GP might be able to help them. Despite such protestations, it is in fact the GPs themselves who are here constructing a moral order of illness categories associated with blame and accountability. Their accounts do not merely describe pre-existing illness categories, but they actively work to *construct* the binary and contrastive nature of physical and psychological medical categories as either more or less culturally acceptable. Patients’ use of ‘a handy ticket’ allows access to a more acceptable category and GPs are the gatekeepers who can issue ‘tickets’ to legitimate membership of this category.

Extract 5: (Interview with GP)

In Extract 1, Dr S stated a preference for the term ‘post-viral syndrome’. At the interviewer’s request, he went on to describe a case of post-viral syndrome from his own experience. At this point in the interview, he has already constructed two different categories of patients: those who are ‘physically a clear and obvious diagnosis’ and another ‘vague group… which we might label psychiatrically as neurasthenia…that might be liable to an ME condition’. The interviewer’s next question asks him to elaborate on this.

1. I mm right (.) so do you think these start out as a post-viral thing to

2. begin with or is it just that they don't present (.) in that way?

3. Dr S I think the first group starts out as post-viral (.) I think the second

4. group is psychiatric (.) psychological disorder (.) er (.) and they've

5. found a label (.) that once upon a time would have been a different

6. label

7. I right so (.) you think the label would have been neurasthenia at one

8. time?

9. Dr S It's a new fad for patients because it's a way of (.) avoiding

10. responsibility for (.) psychological illness (.) if you've got a physical

11. label (.) then it's not your fault (.) <u>nor</u> can you do anything about it.

12. whereas the people who we labelled (.) neurasthenia (.) or weak

13. personalities y'know going back in the old psychiatric textbooks (.)

14. those at least you could confront (.) so it's a useful label for avoiding

15. (.) in <u>some</u> patients (.) er (.) for avoiding er (.) internal conflict

ME is referred to here (in Extract 5) as 'a physical label' (lines 10-11), one that allows patients to avoid their real problems. It is constructed as 'a new fad' (line 9) or 'useful label for avoiding … internal conflict' (lines 14-15). Here the term 'fad' lends a dimension of meaning to ME as a new 'craze' that is currently being taken up by a particular group of patients who are actually suffering from psychiatric conditions. There is nothing new about this patient group ('going back in the old psychiatric textbooks'): This is a construction (in common with Wessley's (1990) reference to 'old wine in new bottles') that shores up the 'facts' of medical knowledge in the face of uncertainty. The category of physical illness is again being contrasted with

psychological illness as the one that such patients want to avoid: According to Dr S, the new 'fad' covers up the underlying truth and allows 'weak personalities' to avoid being confronted by their GPs. This censorial account of avoidance strategies not only constructs psychological illness as a stigmatised category, but also explains why GPs might have difficulty in successfully treating such patients. The next section of analysis further explores how GPs describe patients who mis-appropriate the label of 'ME'.

Media and social influence

The ME controversy has frequently been the topic of media attention, such that the stereotypes are now well known in the popular imagination. In extracts 6-8, GPs talk about the influence of the media on their patients. GPs use a discursive strategy that constructs a basis for contrasting 'genuine cases' with the 'ME bandwagon' who have read about it in the media.

Extract 6: (Interview with GP)

After an earlier question by the interviewer ('have you seen any patients with ME in your practice over the years?') Dr W had begun to differentiate between those who have ME and those who are simply 'tired all the time'. There was an interruption to the interview and this extract is the point where the GP picks up the thread of his narrative.

1. Dr W er what was I saying? (.) yes people with problems of feeling 'tired all
2. the time'(.) which as I say is <u>very</u> common in general practice (.) it's
3. very <u>often</u> a presentation of <u>other</u> stresses (.) problems that are making

4. people feel a lack of energy (.) because they're just (.) weighed down

5. with other problems in fact (.) and also er (.) the-the difficulty with

6. separating them is that (.) quite often people in that situation will have

7. latched onto something like M.E (.) or post-viral fatigue syndrome (.)

8. whatever (.) and will have heard about it as an explanation for being

9. tired (.) whereas they don't really (.) I would put them into a different

10. category (.) perhaps like this person I was talking about before (.) who

11. had really quite an unusual illness (.) he wasn't-he wasn't (.) the

12. typical person who came in feeling stressed and 'tired all the time'(.) it

13. didn't have that sort of pattern to it

Extract 7: **(Interview with GP)**

1. I mm right (.) so do you think these start out as a post-viral thing to

2. begin with or is it just that they don't present (.) in that way?

3. Dr S I think the first group starts out as post-viral (.) I think the second

4. group is psychiatric (.) psychological disorder (.) er (.) and they've

5. found a label (.) that once upon a time would have been a different

6. label

7. […]

8. in the second group (.) generally yes that's a self-diagnosis (.) so

9. they've got symptoms of 'tired all the time' which is chronic (.)

10. associated with low moods (.) and fatiguability (.) and they read about

11. an article that says ME has these symptoms so that's what it is

Extract 8: (Interview with GP)

Dr W has already described a patient who had a firm diagnosis of ME made by a hospital consultant. Here he differentiates between the patient with the firm diagnosis and other people.

I Did he ever bring stuff in for you to read or-or ask for any particular kinds of treatment?

Dr W I don't really think he did (.) we have one or two other people who have (.) you say er (.) other people?

Dr W We've had one or two people who tend (.) who have not had a firm diagnosis of ME made (.) and I would put mo:stly into the category of (.) sort of post-viral syndrome of some sort (.) and what tends to happen is (.) people (.) because of (the media) tend to latch onto ME as a diagnosis very quickly (.) er (.) whereas a lot of these things do seem to get better (.) over a few months (.) six or eight months and looking back on it (.) whether you call it ME or whether you call it post-viral syndrome (.) isn't very relevant (.) because they got better

In extract 6, Dr W describes his criteria for placing a patient into the more common category of 'tired all the time' rather than ME, or post-viral fatigue syndrome. 'Latching on' (Extract 6, line 7; Extract 8, line 10) is described as the typical response of these patients who are easily influenced by whatever they read and hear. Just as the 'Punks' or 'Goths' in Widdicombe & Wooffitt's study of youth sub-culture (1995:

152-3) describe those others who misappropriate the identity of Punk or Goth by superficially conforming to a stereotypical image, so also the GPs categorise those who mis-appropriate an illness label because it superficially matches their symptoms of tiredness.

In Extract 6 (lines 1-2) and Extract 7 (line 7), it is the category of 'tired all the time' that masquerades as the real thing. In the same way that formula stories of domestic 'abuse' (Loseke, 2001) are said to be confused by a so called 'normal' range of violence constructed as an 'ordinary' phenomenon, the recognisable ME case has to compete with the 'tired all the time' story to achieve the legitimate status of 'genuine' illness. Something has to raise it above the level of the ordinary or mundane. In Dr W's account, it is the construction of the unusual nature of the genuine case (Extract 6, line 11) that stresses its departure from the ordinary example. Although Dr W has described this case elsewhere as an *ordinary* physical post viral condition, his construction of its 'unusual' nature functions here to distinguish it as 'genuine'.

In Extract 7, Dr S also constructs two contrasting categories which are differentiated in physical and psychological terms, the first being 'post-viral' and the second defined as 'psychiatric' or 'psychological'. Dr S does not actually say that ME is a psychiatric category, but it is certainly the psychiatric group of patients who have 'read about an article' that seems to describe their symptoms (line 10-11) and have made a 'self diagnosis' (line 8). When contrasted with the group who 'start out clearly as post-viral' the second group are described as having vague, chronic symptoms of 'tired all the time' (line 9) combined with 'low moods' (line 10). However, the phrase 'starts

out clearly' indicates a developing trajectory by which post viral illness can blur into the second category, psychological illness.

In Extract 8, people are said to 'latch onto ME' because of the media. This use of a familiar trajectory is clearly designed as a 'Truth-Will-Out' device (TWOD). This device is described in discourse analytic studies as a way for the true facts of the matter to be established even in the face of conflicting evidence (Gilbert & Mulkay, 1984; Potter & Wetherell, 1987; Potter, 1996). In the face of diagnostic uncertainty, a Truth-Will-Out device can be used to reconcile the contradictions between different versions that can pose a crisis of credibility for medical practitioners. The contradiction between diagnostic uncertainty and the need to display an evidence base for medical practice is resolved by this GP's use of a TWOD to differentiate genuine post-viral illness from the cases that masquerade as such. By categorising the genuine cases as the ones that get better over time he is able to look back and identify them as such. If they get better, (it is argued) this material fact counters the need to have a precise definition of the illness (lines 12-14).

3. Constructing the genuine case in accounts of ME group members.

The 'bandwagon' as the contrast case.

In this section of analysis, ME support group members orient to the reservations that medical practitioners have about ME, indicating that they too are aware of diagnostic misunderstandings, misappropriation of labels and 'bandwagons' to jump on.

Extract 9: (Support group discussion)

1. **J** She said ‘I’ve got ME and my doctor won’t diagnose it’ well I know

2. who her doctor is it’s Dr H so Cathy said ‘well how long have you had

3. it?’ and she says ‘six weeks’

4. **A** .hhh

5. **J** So I said well Dr H won’t diagnose she knows what Angela’s like

6. she’s had it for years she knows that ME isn’t a short term illness er

7. got post-viral fatigue

8. **A** This is it you see people are jumping on the ME aren’t they if they

9. got fatigue for six months (.) they’re saying it’s ME (.) it’s not

10. necessarily so

Extract 10: (Interview with support group member)

BM has been talking about how difficult the illness is for GPs to diagnose.

1. **I** Because that <u>is</u> the problem, isn’t it?

2. **BM** That is the <u>very</u> great problem. If only they could come up with a-a

3. blood test or (.) something (.) that could say ‘<u>yes</u> that shows you

4. have ME’ (.) that would be (.) it would help people <u>so</u> much (.) er

5. I <u>still</u> think there needs to be (.) y’know (.) more investigation into

6. it (.) the root of the problem and all this sort of thing but (.) er if

7. there could be a diagnosis then that would be (.) because (.) well you

8. know (.) it’s the same with all things (.) people jump on the

9. bandwagon (.) and there are people who have (.) are generally unwell

10. but then they say ‘oh I think I’ve got ME (.) I think I’ve got ME’ (.)

11. but after six months (.) they’re okay (.) and er so people who have ME

12. for many years (.) er for outsiders then (.) they look at this and say

13. 'well (.) this person got over it in six months (.) and this person's going

14. on years and years y'know what's the difference?'

The two extracts above come from support group talk and an interview with a member recruited from the ME support group. As members they have a 'stake' in establishing themselves as genuine cases of ME and do so by using 'bandwagon' accounts as a contrastive device. In Extract 9, J's story of the friend who claimed to have 'ME' after only six weeks of illness defines what the GP knows to be true, that 'ME isn't a short-term illness' (line 6). A's illness is contrasted with this example of a 'bandwagon' account (line 8-10). In Extract 10, ME support group member, BM, talks about the difficulty of diagnosing ME. The lack of a definitive medical test leads people to 'jump on the bandwagon' (lines 8-9) and leads to misunderstandings of the serious nature of the illness. BM describes how people who are 'generally unwell' (line 9) are inclined to mis-appropriate the label 'ME' so that 'outsiders' (line 12) perceive the illness as something that can be 'got over in six months' (line 13). The term 'outsiders' here (in Extract 10) constructs her own status and experience as an 'insider', giving greater authority to her claims. Similarly, outsiders lack personal experience that qualifies them to distinguish the 'genuine' case from less serious conditions. BM's rhetorical question (Extract 10: lines 13-14) orients to the effect of 'bandwagon' claims on the social legitimacy of her illness.

In the above extracts (9-10), the participants have worked to distinguish themselves (as genuine sufferers) from people who 'jump on the bandwagon'. In the accounts of GPs (Extracts 6-8) as well as ME support group members (Extracts 9-10) the

'bandwagon' is positioned as a source of confusion that works to undermine the credibility of 'genuine' cases. The ME support group members (Extracts 9-10) attribute 'bandwagon' claims to people who have less serious illnesses and conditions (post viral syndrome or tired-all-the-time), but in the GP's accounts (Extracts 3-8), bandwagon claims are attributed to people who have an underlying psychiatric illness or are motivated to seek a diagnosis of 'ME' as a 'ticket', a way to get access to the sick role and medical attention. The support group members do not define 'bandwagon' cases in psychological terms: these are merely 'outsiders' who have misinterpreted their symptoms because they do not have experience of the genuine illness.

Distancing oneself from the 'bandwagon' in 'tales of the unexpected'

In the three extracts that follow (11, 12, and 13), ME support group members construct their own accounts of the diagnostic process. In such accounts it is the *legitimacy* of the diagnosis that is at stake. In the extracts below, issues of prior knowledge of the illness and the speaker's degree of conformity to social or media influence are the key features of stories of unexpected diagnosis. These accounts of departure from the stereotypical image of ME work to establish the 'genuine' case in contrast to what people might read or hear.

Extract 11: (Interview with support group member)

In response to the interviewer's earlier question ('perhaps you could start by telling me how it all started?') BM has described a series of viral infections that left her

feeling exhausted and unable to carry out the normal routines of her job. Extract 11 describes a visit to the GP.

1. **BM** he said 'well the blood tests show nothing they're perfectly alright' heh
2. heh er but when I told him about the muscles and the problems I was
3. having (.) he sat there and he just said 'I think you might have ME' (.)
4. and I thought 'ME? what's that? Heh heh' because I honestly didn't
5. know anything about it

Extract 12: (Interview with support group member)

1. **Int** How did you feel when the doctor diagnosed your illness as ME
2. after all this time ?
3. (.)
4. **E** well in a way I was relieved that at least it had got a name (.) I wasn't
5. imagining everything (.) er but I was frightened (.) because as soon as
6. he said that I'd got ME I went out and got a book and read about it (.)
7. and I was quite frightened by the thought of how long it might go on
8. for because I'd (1) then I kept thinking 'oh next month I'll be better'
9. er (.) and then when I realised I probably wasn't going to be better next
10. month...

Extract 13: Interview with support group member

In response to the interviewer's request ('I just wanted to ask you to tell me your story really (.) about how things first started') JJ provides a lengthy narrative about the onset of his illness. Extract 13 refers to three sections of that narrative.

1. JJ It didn't come on suddenly-like so many people have a sudden onset
2. y'know following an illness of some sort or they collapsed for no
3. apparent reason (.) that didn't happen to me (.) I just started having
4. strange symptoms I couldn't explain (.) various things you know all
5. sorts of odds and ends of things that happened (.) er and at first I didn't
6. even relate them to each other (.) but eventually I began to realise that
7. it was all tied in and there was something wrong with me
8. […]
9. after all the tests he said 'well I can't really find anything organically
10. wrong with you' he said 'the only thing I can put it down to is ME'
11. well I'd never heard of ME so I said 'yes I've vaguely sort of heard of
12. it but never really (thought about it)' (.) so he told me a bit about it
13. […]
14. so he said 'the main thing is not worry about it' so heh heh that was
15. 1988 (1) er so 'fair enough y'know I've got nothing terribly wrong
16. with me'(.) well he couldn't have been more wrong because far from
17. being well after a while I got worse and worse…

The first account (in Extract 11) describes how BM's illness was diagnosed as 'ME' after her doctor had ruled out other conditions through blood tests. Quoting her own reaction to the doctor's diagnosis, it is stressed that this was not something she had actively sought, 'ME? what's that?', ' I honestly didn't know anything about it' (lines 4-5). Her use of the term 'honestly' orients to the potential for her prior ignorance of the illness to be heard as implausible and for this diagnosis to have been actively sought.

Denying prior knowledge (and therefore motivation) is also a feature of E's account of a diagnosis that was made after she had suffered a lengthy period of illness (Extract 12). Her lack of prior knowledge means that she could not have been socially influenced to seek this diagnosis and her description of how the GP delivered the diagnosis tells us that she was surprised by the news and had previously expected to recover more quickly. Since her admission of 'relief' at the diagnosis could imply she had something to gain by being defined as sick, this is swiftly followed by an account of 'fear' combined with prior ignorance of the illness (Extract 12, lines 5-8). This construction indicates how illness-talk, especially about a contestable diagnosis, is a veritable minefield of risk through which speakers have to navigate (Radley & Billig, 1996). In speaking of her illness as 'ME' or seeking this as a diagnosis, E might risk being defined as seeking 'secondary gain' in the form of social and material benefits that might accompany the sick role. If she lacked prior knowledge of the illness then this counters any possible suggestion that she had been motivated to 'take on' the illness or pursue this diagnosis.

E's account is similar in structure to 'tales of the unexpected' commonly used when people tell stories of paranormal experiences (Wooffitt, 1992). Such accounts display the structure 'at first I thought X, but then I realised Y' (c.f. Jefferson, 1984: Sacks, 1992). Whilst in Wooffitt's analysis, 'tales of the unexpected' bolster the accounts of people who might be heard as impressionable and susceptible, in Extract 12 (lines 11-12) a similar 'stake management' device (Potter, 1996) works to show that E had initially expected to recover quickly, but that it turned out differently. Although the account does not counter an actual accusation of prior motivation or malingering, it is

certainly designed to disable such a response by showing that she had no stake or interest in taking up the sick role.

The account given by JJ (Extract 13) is constructed in much the same way. Beginning with an account that differs from the typical case (lines 1-3), he continues with an account of 'strange symptoms I couldn't explain' (line 4) describing 'odds and ends' (line 5) that were first treated as unrelated (line 6). This account of insignificant 'odds and ends' provides for the very unexpected nature of the events that followed when the 'mystery story' is eventually resolved by the diagnosis of ME. As with E's account, JJ reports that he 'never heard of ME'. Afterwards this 'extreme case formulation' (Pomerantz, 1986) is softened to present a more credible claim, admitting that he 'vaguely sort of heard about it' but 'never really thought about it' (Edwards, 2000). This softer claim orients to the extreme version being unlikely in the circumstances that ME has been widely publicised in the media.

An orientation to the effect of media influence has been a high profile concern in some of the data analysed here and elsewhere (Horton-Salway, 1998). It is paradoxical that illness stories that most closely resemble the classic case or 'formula story' (Loseke, 2001) might also carry a greater risk of being heard as 'bandwagon' cases that have adopted media stereotypes. However, as Sack's has argued, genuine category membership does not only rely on superficial appearances, there must also be reasonable grounds to interpret things that way (Sacks, 1992). So, for example, it is the *lack* of superficial similarity to typical cases, (in Extract 13) combined with JJ's own lack of prior knowledge about the illness and the doctor's initial failure to anticipate the duration of the illness, that set JJ's case apart from the contaminating

influence of prior motive, social and media influence, or even a self-fulfilling prophecy due to the prior expectations of the GP (c.f. Widdicombe & Wooffitt, 1995). Compare this also with Extract 6 (line 11), where Dr W stresses the unusual nature of the genuine case which provides his reasonable grounds to define his example as such.

To summarise the findings in this section, Extracts 11-13 show how ME sufferers describe how they came by a legitimate diagnosis. Speakers describe their illnesses as departing from what they had expected or what is portrayed by media representations and describe how this combined with a gradually emerging awareness of the illness and an unexpected, doctor-initiated diagnosis to establish the genuine character of the case. Avoidance of psychological problems, combined with prior knowledge and media influence are commonly cited by participants as the criteria for categorising cases as false. A typical 'genuine' case is constructed as one where the patient had no prior knowledge or motivation (not based on what they read or hear), a gradual realisation of their illness and a doctor-initiated diagnosis rather than a self-diagnosis.

Discussion

Using the case study of a contested illness, ME/CFS, three features of discourse were examined in this analysis: the constructed and relational nature of illness categories; the construction of 'insider-outsider' patient categories and the moral organisation of those categories.

The analysis highlights some of the ways in which the meaning of illness, illness labels, and the construction of medical and social categories are linked together in

discourse. For example, ME and other labels constitute the meaning of illness. They are used by the GPs and ME group members who struggle to establish the 'genuine' case in the face of medical controversy. Issues about the use of different illness labels (such as ME, CFS and PVS) and their meanings were raised by both GPs and ME support group members. The labels are varied and contestable, but it is their fuzziness and situated inter-changeability that enables an ordering and re-ordering of meaning that functions in variable ways (Macmillan & Edwards, 1998; Horton-Salway, 2004). The analysis has identified the different ways that participants talk about labels and their meanings: For example, different labels refer to different illnesses; different labels have been used as fashion 'fads' to describe the same illness (a form of 'ontological gerrymandering') or some labels do not give an accurate representation of an underlying reality (psychiatric illness). These strategies are like the mundane methods of reasoning that are used to resolve 'reality disjunctures' in courtroom proceedings (Pollner, 1987). Where different versions of reality are stake, these mundane methods are used by the interviewees to identify genuine cases of ME/CFS in contrast to people who 'jump on the bandwagon'.

Participants also use a variety of 'appearance-reality' devices (Edwards, 1998; Heritage, 1984a) to categorise both illnesses and people. These devices appeal to the inner psychological world of intention and motive, delusion, or to cognitive and perceptual processes and establish the reality as hidden behind a superficial appearance of symptoms. For example, the 'taking on' of media stereotypes involves *superficial matching* of symptoms to the stereotype; the *motivation* to do so is the *avoidance* of real underlying psychological problems or the *mis-perceptions* of those who lack knowledge to match their symptoms to the 'genuine' experience. However,

since ME/CFS is a controversial illness, there is no *uncontested* version of the nature of the illness(es) and no definitive way of identifying a 'genuine' sufferer. This medical uncertainty creates a context where GPs must account for themselves in terms of medical legitimacy and ME support group members orient to their social accountability as related to the need for medical legitimacy. It is against this background that labels and 'appearance-reality' devices (above) are used to police the boundaries between the 'genuine' case and the 'bandwagon'.

The analysis of the GP narratives here supports Horton-Salway's (2001; 2002) claims that individual illness identities are produced discursively alongside attributions of physical or psychological illness. Patients are divided (and divide themselves) into social groups in an attempt to construct distinct medical categories. Both Horton-Salway (2001) and Tucker (2004) refer to the stigmatising nature of the category of psychological illness and have shown how ME/CFS sufferers position themselves as having a legitimate physical illness. This paper builds on such claims by showing exactly how the 'stigma' of psychological illness is constituted and embedded in GPs' categorisations of illnesses and patients into genuine and bandwagon cases. Contrast categories are a common feature of both GPs' and ME support group members accounts and the moral ordering of those categories into physical and psychological illness are oriented to in their accounts.

The analyses have also shown how GPs orient to their own accountability as medical gatekeepers who can define what can be counted as legitimate and who can be counted as a genuine sufferer. One way they do this is to try and establish a more solid base of medical knowledge and authority. Another way is to devolve

accountability to the patient: Instead of having to account for their own actions in relation to medical controversy, the GPs describe patients as being responsible for their own illnesses, avoiding their underlying psychological problems and being over-dependent on doctors.

It is not possible to extrapolate from research interviews to clinical consultations, although there is plenty of evidence that interactions in clinical settings are fraught with 'struggle' over physical versus psychological meanings: Banks & Prior (2001) refer to the contests over the definition of the illness and Sharpe (1998) refers to 'bitter debates' between doctors and patients. Nevertheless, some general implications might be drawn from the analysis of interview and support group extracts in this paper. The GPs' accounts of their patients' illnesses indicate that medical categorisation is closely linked with the social categorisation of patients. When talking about ME/CFS, GPs commonly use a dualistic form of reasoning, dividing illness into physical and psychological. Nearly two decades ago, Kirmayer (1988) pointed out that dualistic reasoning has moral implications such that physical illness is largely treated as an 'unfortunate failure of body machinery' whilst psychiatric disorders 'represent a failure of the faculties of reason and self-control' (Sharpe, 2005: 273). The social categorisation of patients into 'person-categories' by GPs works as a *justificatory* practice in accounts that enable them to construct psychological explanations that are associated with censure. Although this finding is based on GPs' narratives in research interviews, the analysis shows a similarity with way that person-categories are built through medical narratives in clinical contexts (c.f. Atkinson, 1995; Hunter, 1991; Soyland, 1994). In both settings, an unhelpful

form of dualistic reasoning (Kendall, 2001) works to constitute psychological illness as a stigmatised category.

It is little wonder that ME support groups work to establish more positive social identities through sharing experience and emphasising the physical status of their illnesses (Horton-Salway, 1998). In such settings, it is the *shared* nature of illness experience that is emphasised. In the research interviews represented here, the business of the interaction is different from that of support groups and the establishment of identity as genuine sufferer is achieved by using strategies that emphasise the *differences* between ME sufferers and others who have more 'trivial' conditions (Extracts 9 and 10). Second, (and paradoxically), by distinguishing their own story from a 'formula story' (Extract 13) ME support group members can establish that theirs as a genuine case of ME/CFS in contrast to media-generated stereotypes (cf. Widdicome & Wooffitt, 1995). The media have often generated images of CFS patients in 'simplistic and stereotypical ways' (Jason *et al,* 1997) and it is this 'media bombardment' (Shaw, 2002) by TV and newspapers that feeds medical controversies and creates the discursive resources for self-diagnosis and 'bandwagon' claims.

Over half of GP consultations deal with medically unexplained symptoms that include fatigue (Chalder, 2005) and despite 48% of GPs in the UK feeling unconfident about making a diagnosis of ME/CFS (Bowen *et al*, 2005), it is they (as diagnostic gatekeepers) who are required to define what counts as legitimate. The accounts of GPs and ME support group members in this paper show some of the common discursive means by which GPs and their patients attempt (in the face of controversy)

to construct a legitimate category and 'police its boundaries' in contrast to the bandwagon.

Transcription Conventions

The symbols used are based on the system developed by Gail Jefferson (1984). Here they have been simplified to suit the style of analysis used in this paper.

(.)	A dot in brackets indicates a hearable pause that is too short to measure.
(3.0)	Numbers in brackets measure pauses in seconds (for example, three seconds).
underlining	indicates emphasis
Ye:ah	A colon indicates elongation of the vowel sound that it follows.
[...]	Indicates where some talk has been omitted from a data extract.
.hhh	Indicates that the speaker is taking an in- breath. Number of h's indicates length of in-breath.

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[1] For an overview of the 'ME debate' as a scientific controversy, see Horton-Salway, 1998.

[2] See Westcare (1994) for a list of diagnostic criteria and typical symptoms. Although formal diagnostic criteria are another forum of debate, the most common and controversial symptom is the chronic debilitating fatigue that is a typical feature of all cases.